Introduction

Having access to suitable housing is a fundamental right for people living with dementia and can enable people to live as well as possible (Twyford & Porteus, 2021). Appropriate housing for people living with dementia is thought to support independent living, maintain social relationships, promote community integration, reduce hospital admissions, delay admission into long-term care and reduce the need for, and costs of, social care (House of Commons, 2018; Twyford & Porteus, 2021). Understanding the advantages and disadvantages of different models of housing with care has been identified as a research priority by people living with dementia (Barrett et al., 2016) and yet, there remains significant gaps in knowledge.

This scoping review focused on people living with dementia in Extra Care Housing (ECH) in the UK. ECH is a model of housing with care that is intended to meet the needs of older people and support independent living for as long as possible. This includes older people living with dementia, however, there remains little evidence as to what works best, and for whom, with respect to ECH for people living with dementia (O'Malley & Croucher, 2005; Dutton, 2010; Twyford, 2016). Darton (2022, p.303) notes that although 'research studies have identified the potential benefits and challenges of providing specialist housing….a number of issues require further research, for example supporting people with dementia.'

ECH has been designed to support 'ageing in place', reducing the need to make potentially stressful relocations in older age (Riseborough & Porteus, 2003). Underpinning the provision of ECH are principles of independence, empowerment, community integration, autonomy, and accessibility (Care Services Improvement Partnership, 2006; Barrett et al., 2016). In practice, this involves supporting independent living in self-contained accommodation (usually own flat/apartment within a larger complex), with the flexible onsite provision of 24-hour care, and access to a range of communal activities and facilities (Evans et al., 2017; Riseborough et al., 2015). ECH is primarily housing provision and has a clear distinction from more institutional residential care settings (Riseborough & Porteus, 2003, p. 23). The care element provided in ECH is separately funded from housing-related costs; that is, it must be funded through adult social care, privately, or a combination of both (Evans et al,. 2020). Not everyone living in ECH will require care at all times, but the flexibility of provision allows for a diverse population of people to live alongside each other and receive appropriate input as and when needs change. There is significant diversity across the design, management, and resident population of ECH schemes in the UK. For example, differences exist in the location, size, housing and care provider relationship, care capacity, tenure, and availability of specialist support (Atkinson et al., 2014; Croucher et al., 2006).

Most schemes provide integrated models of ECH, whereby people living with dementia live alongside people living without dementia (Barrett, 2020b; Twyford, 2016). However, other models include ECH schemes with separate units or wings that are specifically for people living with dementia (separated model), or specialist ECH schemes that are only for people living with dementia (specialist model) (Barrett, 2012).

The benefits of ECH for the general population are now more widely understood (Darton, 2022; Evans & Vallelly, 2007; Holland, 2015), although it should be noted more recent research has suggested financial pressure can result in more task-centred care (Cameron et al., 2020; Darton, 2022). However, there are approximately one fifth of residents in ECH living with dementia (Barrett, 2020a) where little is known about their experiences of different models of ECH (Dutton, 2010; O'Malley & Croucher, 2005; Twyford, 2016). This presents a fundamental gap in knowledge. Considering the advantages and disadvantages of ECH for people living with dementia is therefore the focus of this scoping review.

Methodology

A scoping review methodology was employed (Arksey & O'Malley, 2005) with the review question:

> *What are the key advantages and challenges of living in ECH for people living with dementia?*

A scoping review was chosen to map out and summarise the body of literature available with respect to extra care housing provision for people living with dementia. The intention was to determine the focus and volume of literature such that future directions for research could be identified (Arksey & O'Malley, 2005; Munn et al., 2018). The focus was not on the quality of evidence, nor on determining evidence-based best practice, but rather, on the range and type of evidence available. This permitted the inclusion of grey literature and a range of methodological approaches. Such an approach has some limitations given that a scoping review does not appraise evidence quality in the way that a lengthier systematic review process might (Arksey and O'Malley, 2005). In addition, the scoping review requires decisions to be made as the breadth and depth of literature included. With respect to this study, it is acknowledged that limiting literature to the UK could have excluded additional international evidence, but the decision was such based on the diversity of ECH terminology/models across the world, varying legislation, and cultural norms.

The review question focused specifically on people living with dementia in ECH but included the views of professionals, and people without dementia, who contribute to the experience of living with dementia in ECH. As per scoping review methods, this review considers the extent of knowledge, but does not address the quality of studies included (Arksey & O'Malley, 2005).

Key search terms were identified:

> "extra care" OR "housing with care" OR "retirement villages" OR "specialist housing" OR "integrated housing" OR "very sheltered" *(title/abstract/ keywords)*
>
> AND dementia OR Alzheimer's OR "cognitive impairment" (*anywhere in the article, not restricted to the title*)

The search was confined to studies based in the UK from January 2000-September 2021. Given the diverse nomenclature used to describe ECH, the search terms were expanded to include other commonly used descriptors. The following databases were searched: MEDLINE, ProQuest Central, Social Care Online, PsychINFO. Post hoc inclusion/exclusion criteria (see Table 1) were established based on increased familiarity with the literature (Arksey & O'Malley, 2005). Studies that included a subsection of results with respect to people living with dementia were included if results could be differentiated from more general observations about older people living in ECH. In addition to database searching, reference lists were hand-searched to identify additional literature. Searching of relevant websites (e.g. HousingLIN, Housing and Dementia Research Consortium) and consultation with a panel of eight experts, including two user representatives, also helped provide advice and guidance to inform and validate the findings of this scoping review (Arksey & O'Malley (2005).

A total of 174 references were identified. After duplicate removal, 152 titles and abstracts were subject to standard title and abstract screening. 74 publications were identified as relevant and full text screening followed. From these, 37 were identified as meeting the inclusion/exclusion criteria for this scoping review. Relevant studies were tabled (Ritchie and Spencer, 1994) to synthesise and interpret data into meaningful themes.

Table 1 Inclusion and exclusion criteria for studies in the review

Inclusion criteria	Exclusion criteria
Grouped housing for people living with dementia that offers care and support to residents who are tenants or owners	Individual housing
	Residential/nursing/care homes
Grouped housing for older people including those living with dementia that offers care and support to residents who are tenants or owners	Grouped housing without care and support
	Marketing studies, physical design guides, purely descriptive studies, intervention studies non-specific to the ECH model, studies considering motivation to move in
UK-based empirical studies that answer the research question	
Evaluations, PhD theses	Commentaries, discussion, or opinion pieces
Studies published between January 2000-August 2021	Literature reviews
	Non-UK based studies
	Studies published before January 2000 and after September 2021

Results

A note on study methodology

The majority of research reported on in relation to living with dementia in ECH is focussed upon qualitative data derived from interviews or surveys with ECH staff, family carers or residents. Whilst qualitative data can provide rich and detailed insight into the lived experience of dementia, the source of data supporting conclusions is not always clarified in research reports….

There is qualitative evidence that ECH can support quality of life for people living with dementia (Evans et al., 2020; Twyford, 2018; Vallelly et al., 2006). Darton and Callaghan (2009) observed that people living with dementia in ECH showed less deterioration in cognitive and physical functioning relative to those who moved into care homes over the same period, concluding that ECH may be effective in promoting wellbeing and maintaining independent living skills when living with dementia. This was based on… However, there is significant complexity given the different factors that can impact upon an experience of living in ECH. Findings are presented as an overview of the key themes with regards to the advantages and challenges of ECH in the UK for people living with dementia.

Advantages

Ethos of promoting independence

The concept of ECH is underpinned by the promotion of independence. This ethos is an advantage for residents, family carers, staff, and providers (Barrett, 2020b; Barrett et al., 2016; Evans et al., 2020; Twyford, 2018; Vallelly et al., 2006). Independence in ECH is promoted through the freedom to come and go from the scheme, having maximum opportunity to do things for oneself, and being able to choose what, where, and with whom to spend one's time (Evans et al., 2020; Evans et al., 2007; Twyford, 2018; Vallelly et al., 2006). Independence may be reinforced through the ownership of one's home (either through purchase, tenancy, or leasehold) and the autonomy to control the use of that private home (Barrett et al., 2016; Burns et al., 2009; Vallelly et al., 2006).

ECH is a model which can support couples to live together in an environment that provides appropriate care and support for both parties as required (Evans & Means, 2006). Non-resident family members can also underpin independent living through (support with) shopping, meal preparation, managing finances, housework, and trips away from the scheme (Vallelly et al., 2006). However, the small size of flats can present barriers to family relationships in that it is not always possible for non-resident family members to stay overnight (Evans et al., 2020). This can undermine living well and contribute towards feelings of loneliness and social isolation (Evans et al., 2020). However, non-residents can be encouraged to join in social activities in the ECH scheme (Burns et al., 2009; Garwood, 2008a) and the continued involvement of family and friends can create a more homely environment than other institutional settings (Vallelly et al., 2006).

The provision of flexible and specialist care and support

A key element of ECH is the provision of 24-hour flexible care and support. This is particularly advantageous to people living with dementia who experience changing needs across time (Twyford, 2018). Flexible provision can enable people to remain ageing in place for longer, therefore reducing potential relocation disruption and distress (Barrett, 2015; Barrett et al., 2016; Croucher et al., 2007;). Staffing flexibility across ECH schemes varies, but advanced planning for unplanned support, or the provision of a floating staff member, can provide flexibility that is reactive to the changing day-to-day needs of residents with dementia (Cameron et al., 2020; Evans et al., 2020; Garwood, 2008a; Twyford, 2018). Flexible care provision in ECH is a key advantage that may sustain independent living and reduce the risk of hospital admission for residents with dementia (Brooker et al., 2011; Routledge et al., 2016).

Having a familiar team of staff onsite can be a further advantage in ECH that maximises person-centred care and promotes the continuance of daily routines and preferences. (Barrett, 2012; Evans et al.,

2020; Evans et al., 2007; Vallelly et al., 2006). Barrett (2012) noted that smaller schemes were better able to build relationships between staff, residents, and family. Specialist models are often smaller and have higher ratios of staff-to-residents, therefore can facilitate more intense levels of support to individual residents (Barrett, 2012). In turn, this can make it easier to manage disorientation and walking with purpose (Burns et al., 2009; Barrett, 2012; Vallelly et al., 2006;). Research has suggested that specialist models of ECH might be better able to support people living with dementia to age in place for longer, (Barrett et al., 2016).

Key to the effectiveness of staff support is the provision of specialist dementia training (Barrett, 2020b; Brooker et al., 2011; Burns et al., 2009; Croucher et al., 2007; Evans & Vallelly, 2007; Evans et al., 2007). Staff training is reported to improve the provision of person-centred care, increase the willingness and ability of staff to manage more complex symptoms of dementia, improve risk management, better manage walking with purpose, and increase the staff/scheme willingness to customise the environment (Barrett et al., 2020; Burns et al., 2009; Evans et al., 2020; Evans et al., 2007). Such outcomes can make ECH particularly advantageous to different people living with dementia.

A staffing intervention specific to the context of ECH is the provision of 'locksmiths' (now called Dementia and Mental Wellbeing Enablers) under the 'Enhancing Opportunities Programme' (EOP) by a particular large provider of ECH in England (Brooker et al., 2011). EOP is a whole-scheme approach that includes having specialist staff, leadership, training, individualised care work, and activity provision (ibid.). An evaluation found that EOP had a positive impact on quality of life when schemes were well-staffed. The locksmith role involved liaising between a resident living with dementia, services, and activities. This role was particularly valuable in ensuring residents living with dementia had access to healthcare and social support, such that it ensured they were enabled to enjoy an enriched lifestyle, with maximum dignity, and opportunity for self-reliance.

Generating a sense of safety and security

A significant benefit reported for ECH is the sense of safety and security that it generates for residents living with dementia, family carers, and staff (Barrett, 2021; Barrett et al., 2016; Burns et al., 2009; Evans et al., 2020; Garwood, 2008a; Twyford, 2018; Vallelly et al., 2006;). A survey of ECH managers suggested that this was a key motivation for moving to ECH, and a significant benefit experienced (Barrett, 2020b). The ability of staff to respond, the use of assistive technology, the safety of communal facilities, and the contained nature of facilities available onsite, contribute to the increased

sense of safety (Evans et al., 2011; Evans et al., 2020; Routledge et al., 2016;). Appropriate use of technology can create an environment that reduces levels of distress or confusion, maintains independence, supports ongoing use of skills (where otherwise increased care and support might have been required), and ensures that a rapid and appropriate response is available should it be needed (Barrett et al., 2019; Burns et al., 2009; Evans et al., 2007; Evans et al., 2011).

For family carers, the knowledge that staff are available onsite 24-hours per day, together with an alarm system, are reported to provide reassurance that might otherwise have been absent when a person was living in private independent accommodation (Vallelly et al., 2006). A study of frontline practitioners has noted a similar potential benefit (Verbeek et al., 2019). Such reassurance can alleviate stress for family carers, improve relationships between the carer and the cared for, and support family carers to continue provision of informal care (which could be key to delaying admission to institutional care) (Barrett et al., 2016; Vallelly et al., 2006;).

Social inclusion and community integration

A key concept underpinning ECH is social inclusion that a shared group living environment can provide. This is particularly beneficial for people living with dementia who may be at increased risk of loneliness and social isolation (Alzheimer's Society, 2013). Social opportunities are offered through activities, facilities, and informal peer-to-peer interactions that the group living environment provides (Barrett, 2020b; Evans et al., 2019; Evans et al., 2020; Twyford, 2018; Vallelly et al., 2006). Activities may be organised or informal, whilst onsite facilities (e.g. shop, café, garden) can be a focal point for social interaction, as well as an opportunity to continue independent living skills (Evans et al., 2020; Twyford, 2018; Vallelly et al., 2006). Exerting choice and control with respect to accessing social opportunity aligns with the ethos of promoting independence and can offer individuals the chance to undertake activities that uphold a sense of identity (Barrett et al., 2016; Evans et al., 2019; Twyford, 2018; Vallelly et al., 2006).

As well as organised activities, the ECH group living environment offers opportunity for friendships and informal peer support between people living with, or without, dementia (Barrett, 2015; Evans et al., 2020; Means et al., 2006; Twyford, 2018; Vallelly et al., 2006). Some residents living with dementia have reported that an advantage of integrated ECH is the promotion of dementia awareness and tolerance that living alongside people with, and without, dementia can provide (Barrett et al., 2016). As well as friendship opportunities, staff from ECH schemes have suggested that relationships between residents can support safer walking with purpose by alerting staff or supporting with

wayfinding (Barrett et al., 2020). Such relationships are suggested to support social and community inclusion, which, in turn, is beneficial for people living with dementia (Twyford, 2018).

Whilst integration within the scheme is important, integration with the wider community is also reported to be beneficial for people living with dementia. This can reduce the risk that the ECH environment feels overly institutional and constrained (Evans & Vallelly 2007; Routledge et al., 2016; Vallelly et al., 2006;). A loss of relationships within the external community has been reported to contribute to feelings of loneliness in specialist ECH provision (Evans et al., 2020). Onsite facilities also offer opportunity for family involvement, intergenerational activity, and engagement from wider community residents, all of whom can be encouraged to make use of facilities (Evans & Vallelly, 2007; Evans et al., 2020; Twyford, 2018; Routledge et al., 2016; Vallelly et al., 2006;). Such opportunities for wider integration are reported to improve the sense of independent living to which ECH aspires (Barrett, 2015; Barrett et al., 2016; Barrett et al., 2020; Vallelly et al., 2006) and thus, can contribute to an optimal culture that is advantageous for living well with dementia.

Physical design and an enabling environment

It is well established that environmental design can impact the abilities of people living with dementia (Alzheimer's Disease International, 2020). It is reported that many purpose-built ECH schemes are rooted in dementia friendly design and thus, can provide an enabling environment that supports safe and independent navigation around a scheme (Barrett, 2020b; Barrett et al., 2020; Twyford, 2018; Vallelly et al., 2006). Features such as maximising light, adding landmarks, colour-coding locations and routes, visible cupboards, accessible signage across public and private spaces, and effective design and access to outdoors spaces can be advantageous in supporting people living with dementia (Barrett et al., 2020; Evans et al., 2019; Twyford, 2018; Vallelly et al., 2006). Including places to rest, marking indoor and outdoor walking routes, adding points of interest along the way, and encouraging/discouraging access to areas, are reported more likely to feature in ECH than other retirement housing settings (Barrett et al., 2020). Whilst dementia friendly design is not unique to ECH, nor is it present in every ECH scheme, where it is successfully integrated, it is of benefit to people living with dementia.

In addition to design, the physical location and size of ECH schemes can impact upon the relative advantages or challenges of ECH for a person living with dementia. Garwood (2008b) has suggested smaller ECH schemes are easier to navigate for people living with dementia, with larger villages being less suitable for residents living with dementia. However, smaller schemes may also have less onsite

amenities, which may reduce independence and social opportunity (Evans et al., 2020; Garwood, 2008a; Twyford, 2016). Easy access to the local community (e.g. proximity to shops, transport links, and nature opportunities) can be beneficial to living well and maintaining a level of independence in the wider community (Evans et al., 2020; Evans et al., 2019). However, aspects relating to optimum size, economies of scale, and potential differences between integrated and specialist-built environments also remain under explored in literature.

Integrated service provision

Integrating ECH into a wider policy approach for older people within a locality can position an ECH scheme as the central location from which other health and social care services can be delivered (Garwood, 2008a; Vallelly et al., 2006). This has the potential to deliver better joined up services. ECH schemes can have onsite visits from GPs, CPNs, social workers, and other community-based services (Burns et al., 2009; Cameron et al., 2020); in turn, providing economy of scale for services. Residents living with dementia can find their access to healthcare and other services improved and thus, preventable health problems can be identified and managed, therefore reducing the risk of an acute health crisis (Garwood, 2008a; Brooker et al., 2011). Furthermore, where hospital admission does occur, the length of stay may be reduced if the onsite care provision is readily able to adapt to changes required (Garwood, 2008a). This is particularly advantageous to people living with dementia who may experience significant distress in hospital and benefit from consistency of staff and location (Brooker et al., 2011). However, it has been noted that access to health and social care professionals in ECH is not always effective and can provide a challenge for residents living with dementia (Barrett, 2020b; Blood, 2013; Evans et al., 2007; Means et al., 2006; Vallelly et al., 2006). This might be particularly so when the resident living with dementia requires a higher level of support to access health services than staff or non-resident family are able to provide (Blood, 2013). There is not enough detail or evidence to suggest how this model of better integrated provision can be best provided across different sizes and types of ECH scheme.

Challenges

In addition to potential advantages that ECH can provide, there are challenges that people living with dementia can encounter when trying to access or live in ECH. These include barriers to entry, tension between independence and support, advancing dementia, resource constraints, stigma and social exclusion, and a disabling environment.

Barriers to entry

Several challenges exist that can prevent people living with dementia from being able to access ECH as their chosen housing option. It is generally accepted that people living with dementia will benefit most from moving into ECH when they are still able to navigate around a new environment, establish new routines, and build new social relationships (Barrett, 2012; Darton & Callaghan, 2009; Twyford, 2018; Verbeek et al., 2019). However, a lack of availability can prevent or delay the choice to move to ECH. This can mean symptoms of dementia might progress, making ECH no longer the most appropriate choice (Barrett et al., 2016).

A study exploring the views of frontline practitioners found that staff did not believe ECH was suitable for people living with dementia who needed care at night and questioned how ECH provision fitted with alternative care at home or residential care home options (Verbeek et al., 2019). Practitioners largely reported that keeping someone in their own home was preferable because it avoided unnecessary moves that could result in loss of independence. Indeed, practitioners noted that there ECH could not guarantee to prevent later disruptive moves to institutional care (ibid.).

The lack of knowledge and understanding that frontline staff have with respect to what ECH is, and who might benefit from living in ECH, is a significant barrier for people living with dementia being able to seek advice and understanding of what options for housing and care are available (Porteus & Twyford, 2021). Furthermore, this lack of clarity has impacted the development of ECH for people living with dementia (Verbeek et al., 2019).

Entry criteria for ECH are reported to be flexible and based upon the existing balance of needs in the resident population (Darton et al., 2009; Garwood, 2008a; Twyford, 2018). However, an increasing threshold at which local authorities will provide care has resulted in growing numbers of people with high levels of need moving into ECH (Twyford, 2018). This can also mean that people with higher levels of physical health needs are prioritised for entry over a person with dementia with lower levels of existing need. Assessing suitability for entry may be further complicated by a lack of information about a person's diagnosis and symptoms upon application for entry into ECH (Lipman & Manthorpe, 2017; Verbeek et al., 2019). In turn, this presents a challenge in identifying those who may most benefit from a specialist scheme or specialist staffing support (Lipman & Manthorpe, 2017).

Once a place has been identified and offered to a person with dementia, a further barrier may arise with respect to whether that person has legal capacity to understand and enter (or exit from) a tenancy or leasehold agreement (Barrett, 2012; Barrett et al., 2016; Burns et al., 2009;). This process

is particularly challenging if a person is deemed not to have the capacity and does not have a Lasting Power of Attorney or family member to support with decisions (Barrett, 2012). Such challenges can prevent or delay moving in, and the potential resident might deteriorate past the point at which entry into ECH would have been an optimal choice (Barrett, 2012; Burns et al., 2009).

Tensions between independence and support

A key challenge in ECH for people living with dementia is achieving a balance between retaining independence and receiving an appropriate level of support that safeguards potentially at-risk individuals (Evans et al., 2020; Evans & Means, 2006; Twyford, 2018; Vallelly et al., 2006). This can relate to issues centred upon safeguarding and deprivation of liberty (Barrett, 2015). It can be further complicated by family or other resident's understandings of what level of support ECH can practically, and legally, provide, as well as a person's right to make unwise decisions (Barrett, 2015; 2020b; Cameron et al., 2020; Evans et al., 2020). A case study of a specialist ECH scheme reported that family expectations were more akin to those of traditional residential care (Burns et al., 2009). Achieving a balance between independence and support is a subjective decision and requires a complex negotiation and understanding between staff, residents, and family members within the confines of available staffing resources, the physical environment limitations, assistive technology availability, and the legal ramifications of how levels of support might impact upon a person's rights (Barrett, 2015; 2020b; Garwood, 2008a). This is a significant challenge and becomes more prevalent as a person's dementia advances and support needs increase.

A particular issue in ECH relates to how ECH staff can support people with the freedom to come and go from a scheme (Barrett, 2015; 2020b; Garwood, 2008). Restricting this ability has implications for both safeguarding legislation and Deprivation of Liberty Safeguards (DoLS), presenting challenges to residents, staff, and ECH providers (Barrett, 2015; 2020b; Barrett et al., 2020). At present, DoLS issues are reported to be more of an issue by staff in ECH compared with other retirement living schemes (Barrett et al., 2020).

Other safety issues reported to be difficult to manage in ECH for people living with dementia are risk of falls, misuse of household items, or disorientation inside and/or outside the scheme (Barrett et al., 2020; Evans et al., 2020). Relative to institutional care, supervision in ECH is much reduced and indeed, the onus to ensure safety can encroach upon independence and autonomy (Barrett et al., 2020; Evans & Means, 2006; Evans et al., 2020). Taking a person-centred approach to risk is important (Evans & Means, 2006), and yet, without appropriate staff training or organisational support, this can present

a challenge (Barrett et al., 2020). Assistive technology could be advantageous in supporting this balance of independence and safety, but reports suggest it is often underused due to lack of professional knowledge, financial constraint, or concerns related to liberty safeguards (Evans et al., 2019; Evans et al., 2007; Garwood, 2008a; Twyford 2018; Vallelly et al., 2006). Achieving the balance between independence and support is a significant and complex challenge, that requires much more evidence to underpin good practice and develop policy that supports all parties involved in the challenge.

Managing advancing dementia

Managing more advanced symptoms of dementia in ECH is a significant challenge identified within this review. Advancing dementia can lead to a person being denied entry to, or encouraged to move out of, ECH (Barrett, 2012; 2020; Barrett et al., 2016; Bernard et al., 2007; Croucher et al., 2007; Evans & Vallelly, 2007; Garwood, 2008a; 2008b; Verbeek et al., 2019). Reasons given for moving people out include people becoming a risk to themselves or others, excessive care costs, an inability to safely manage walking with purpose, risks associated with leaving the building, self-neglect, unmet care needs, isolation/social needs not being met, the instability of a person's condition, perceived excessive use of alarm cords (especially at night), conflict with other staff/residents, increased distress, challenges communicating, a need for more specialist healthcare input, and a perception that there is no longer benefit in the potential advantages that ECH can provide (Barrett, 2012; 2020; Barrett et al., 2016; Barrett et al., 2020; Cameron et al., 2020; Croucher et al., 2007; Evans et al., 2020; Garwood, 2008b; Vallelly et al., 2006). In effect, the advancing symptoms of dementia seem to make the balance between independence and support unmanageable, prompting a (potentially disruptive) move to alternative accommodation (Evans et al., 2020). There is varied evidence as to whether schemes have specific criteria at which exit is triggered (Barrett, 2020b; Twyford, 2018). A lack of criteria might present challenges for persons seeking clarity about who ECH is most appropriate for, although explicit guidance could equally be unhelpful if it is unduly restrictive (Garwood, 2008a). This is challenging for all parties in understanding who might benefit from ECH and when that benefit is no longer viable.

The reality of resourcing flexible care

The provision of flexible care in ECH is theoretically a great advantage for people living with dementia. However, the reality of resourcing flexible care, alongside increasing levels of need, is reported to compromise the ability of staff and ECH schemes to provide the care approach thought so

advantageous (Cameron et al., 2020; Evans et al., 2020; Garwood, 2008a; Vallelly et al., 2006). Financial pressures, low paid staff, staffing shortages, difficulties contracting flexibility, and poor working conditions can all create barriers to the provision of consistent, but flexible, support (Cameron et al., 2020; Evans et al., 2020; Garwood, 2008a; Vallelly et al., 2006;). Organising staff rotas around high levels of unpredictable need can be particularly challenging in specialist dementia ECH facilities (Cameron et al., 2020). A lack of responsive and flexible care can undermine a person's ability to access communal facilities, social activities, and maintain their skills (Vallelly et al., 2006) and thus, resource constraints could undermine the ability of people living with dementia to live well in ECH.

ECH staff have noted that resource limitations can result in increasingly task-centred approaches more akin to traditional institutional models than the flexible, person-centred support promised by ECH (Barrett, 2021; Cameron et al., 2020; Evans et al., 2020; Johnson et al., 2019;). Staff report that supporting mental wellbeing or social activity provision for people with dementia can become secondary to supporting physical wellbeing and thus, find that their ability to focus on the former is constrained (Evans et al., 2020; Twyford, 2018; Vallelly et al., 2006;). The privacy of owning one's flat can actually exacerbate a sense of isolation if additional support (e.g. prompting or orientation) is unavailable to access communal activities or facilities (Evans & Vallelly, 2007; Evans et al., 2020; Cameron et al., 2020; Vallelly et al., 2006). The availability of 'green care' activities in care homes compared to ECH, demonstrated that levels of support to engage people living with dementia could be lacking in ECH, (Barrett et al., 2018). A lack of support to access activities can contribute to decreasing numbers of residents taking part in activities and thus, undermine the overall social and communal aspect of ECH that is suggested to be key (Cameron et al., 2020).

Employing care staff and housing staff from different providers, or regular use of agency staff, can add an additional layer of difficulty which can confound roles and accountability with regards to managing person-centred support, promoting social engagement, and supporting wider resident population dynamics (Twyford, 2018). This can impact upon the person living with dementia who might find it challenging to access the level of support required. Different schemes have a variety of organisation configurations requiring further research to explore how these approaches support people with dementia to live well.

Social exclusion, loneliness, and stigma

A significant issue in ECH is the impact of social exclusion and stigma that some people living with dementia experience when living alongside people without dementia. Attitudes of staff or other

residents can impact upon the ability of people living with dementia to thrive in ECH (Barrett, 2012; 2015; 2020b; Barrett et al., 2016; Barrett et al., 2018; Cameron et al., 2020; Evans & Vallelly, 2007; Evans et al., 2020; Twyford, 2018; Vallelly et al., 2006;). In a study exploring six ECH schemes, residents with a cognitive impairment were less socially integrated and reported some loneliness (Evans & Vallelly, 2007). Staff in ECH have suggested that their main challenge is managing the stigma and negative attitudes directed at residents living with dementia (Barrett, 2012; Evans & Vallelly, 2007). Reports of stigma from other residents are common across the literature (Evans & Vallelly, 2007; Evans et al., 2020; Garwood, 2008b; Twyford, 2018; Vallelly et al., 2006). Residents without dementia have questioned the ability of ECH to meet increasingly complex needs of people living with dementia (Cameron et al., 2020) and are frequently reported to be upset by walking with purpose (Bernard et al., 2007), or a belief that people living with dementia are incompetent and unable to interact or contribute socially (Evans et al., 2020). Negative attitudes can be exacerbated by the provision of specialist dementia activities in integrated schemes, or a belief that certain activities cannot be provided because of the presence of residents living with dementia (Evans et al., 2020).

Within integrated schemes, stigma from residents without dementia is thought rooted in their expectations of living in ECH, as well as a lack of understanding about dementia (Barrett, 2015; Evans et al., 2020). Within specialist schemes, there is conflicting evidence in relation to stigma. A single site specialist case study suggested that there was little stigma attached to the scheme and it was well integrated in the small local community (Garwood, 2008a). However, other specialist provision, especially where people with dementia live separately, has been suggested to serve as a focal point at which stigma is directed (Barrett, 2015). It should be noted that where residents receive dementia awareness sessions in integrated schemes, stigma was reduced and peer support more likely (Barrett, 2015). This finding suggests that whilst stigma may be a significant challenge for people living with dementia in ECH, the group living environment also offers opportunity to address issues as a whole community and therefore, reduce the stigma that a person living with dementia might often encounter. More research exploring the different experiences of stigma in different types of ECH is required.

Disabling environment

Where good design can be enabling, poor design in ECH can be disabling and present challenges for residents with dementia (Barrett, 2015; Barrett et al., 2016; Bernard et al., 2007; Burns et al., 2009; Twyford, 2018; Vallelly et al., 2006;). This can be a result of the size, location, or design of the scheme. For example, the geographical location of the ECH scheme might limit autonomous access to the wider

community, resulting in loss of skill and potential increased feelings of social isolation and institutional living (Evans et al., 2020). Scheme size and use of space has important aspects for consideration. Integrated schemes are often larger, creating a greater challenge in orientation and navigation for a person living with dementia (Barrett, 2015; Bernard et al., 2007). Reducing the size of communal spaces to create a more 'homelike' feel may also have unintentionally negative consequences. A small specialist scheme decreased the size of communal facilities to reduce feelings of institutional care, but in doing so, prevented residents from all being able to access social meals or activities due to limited capacity (Garwood, 2008a). In turn, this impacted negatively on the ability to develop a community-like feel. A similar finding with respect to a small, shared dining area has been reported more recently (Evans et al., 2020). Additionally, smaller dementia-specific facilities may not afford the same access to communal amenities, which this can reduce opportunities for social interaction and autonomous activity (Evans et al., 2020).

Poor design can make navigation inside and outside the scheme particularly challenging for residents living with dementia (Barrett et al., 2016; Twyford, 2018). The size of a building, similarity of corridors, poor lighting, or the need to access separate parts of a complex can all contribute to an environment that is disorienting, confusing, and difficult to self-navigate (Bernard et al., 2007; Burns et al., 2009; Evans et al., 2020). Furthermore, design issues such as patterns, modern taps, hidden toilet cisterns and fob-door entry systems can present challenges to people with different symptoms of dementia (Barrett, 2020b). Within integrated schemes, there may be a tension between dementia-friendly design and the aesthetic appeal intended to boost commercial viability of a scheme (Twyford, 2016; Evans et al., 2020). Some staff have reported that they believe dementia-friendly design can create an unwanted institutional feel in ECH (Barrett et al., 2016; Evans et al., 2020), whilst feared or actual costs of adaptations and health and safety regulations can present barriers to the making of environmental changes that might be beneficial (Lipman & Manthorpe, 2017). Issues related to design, size and location suggest that there is a tension between commercial viability, economy of scale, and the optimal ECH environment. However, more research is needed to understand what works best for whom.

Conclusion

There is a need for more research into housing options for people living with dementia to ensure that people are provide with evidence-based information with respect to their housing choices (Twyford & Porteus, 2021).

This scoping review has highlighted advantages and challenges within ECH for people living with dementia. Whilst the benefits of ECH can promote independence, social inclusion and provide a safe and empowering place to live, each of these elements can be a challenge to deliver or be undermined by poor practice. Tensions exist between the balance of independence and support, as well as between commercial aspirations and the optimal living environment. There is constant appreciation that person-centred planning and support, specialist staff training, flexible provision, social opportunity, and good design can be advantageous to residents living with dementia, particularly so, if that person relocates to ECH during earlier stages of dementia. However, the realities of group living, compounded by limited staff resources, a lack of understanding about what ECH, poor environmental design, and increasingly high levels of need amongst the resident population can undermine the potential benefit that a person living with dementia can get from ECH.

How ECH can best support people to live well with dementia requires further research to address the significant gaps in the evidence base and to determine how different models of ECH might support different people to live well. It should also be noted that there is a notable lack of evidence from the perspective of people living with dementia in ECH. Previous literature reviews on supported or specialist housing for people living with dementia noted a similar gap and little seems to have changed in the last decade (Dutton, 2010; O'Malley & Croucher, 2005). A recent systematic review of living with dementia in broader supported housing has also suggested that more high-quality research is needed, that includes the perspectives of people living with dementia, and considers how models of supported housing can support independence, autonomy, and social connection (Smith et al., 2021).

Further research adopting a qualitative approach that captures the voices of those living with dementia in extra care housing together with those managing and commissioning ECH will go some way to meeting the need for evidence-based information provision called for by the APPG inquiry (Twyford & Porteus, 2021). Exploring how these different advantages and challenges are managed within different models of ECH will have benefit to all parties.

Limitations: This review excluded many papers because of an inability differentiate findings for people living with dementia from general population. Others were included based on small anecdotal reports of residents living with dementia, but these authors often overlooked the relevance of dementia in their broader conclusions. Whilst some literature rooted in generic ECH populations will be relevant to some people living with dementia, more attention is needed to identify the ways in which ECH can support or undermine the ability of people living with dementia to live well alongside others in ECH. Furthermore, the number of papers included in this review exaggerates the number of studies that have been undertaken, with several studies resulting in multiple publications.

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